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Nurses assistance to children in palliative care: a study in the light of Jean Watson's theory

Assistência de enfermeiros a crianças em cuidados paliativos: estudo à luz da teoria de Jean Watson

Asistencia de enfermeros a niños en cuidados paliativos: un estudio a la luz de la teoría de Jean Watson

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Abstract

Objective: To understand the care provided by nurses to children with cancer in palliative care in the light of Jean Watson's Theory. **Method:** Qualitative study, based on Jean Watson's theory, carried out with ten clinical nurses from a reference hospital for cancer in João Pessoa, PB. The collection of empirical material took place between October and December 2020, through the semi-structured interview technique, later analyzed under the Content Analysis Technique. **Results:** The nurses' testimonies brought strong reflections on knowledge in the field of oncology nursing, with an emphasis on assistance to children in palliative care, since the strategies implemented in this scenario are consistent with Jean Watson's Theory, based on the elements contained in the Clinical Caritas Process. **Conclusion and Implications for practice:** The role of nurses based on humanized care, with the scope of promoting comfort and pain relief, and dialogical, playful and transpersonal practices, is essential in this disease process. In this way, the identified strategies may contribute to the clinical practice of nurses, when caring for children with cancer in palliative care, based on Jean Watson's Theory.

Keywords: Palliative Care; Child. Neoplasm; Nursing; Nursing Theory.

Resumo

Objetivo: Compreender a assistência de enfermeiros a crianças com câncer em cuidados paliativos à luz da Teoria de Jean Watson. **Método:** Estudo qualitativo, tendo como referencial a teoria de Jean Watson, realizado com dez enfermeiros assistenciais de um hospital de referência em câncer de João Pessoa, PB. A coleta do material empírico ocorreu entre outubro e dezembro de 2020, por meio da técnica de entrevista semiestruturada, posteriormente analisado sob a Técnica de Análise de Conteúdo. **Resultados:** Os depoimentos dos enfermeiros trouxeram reflexões contundentes acerca dos conhecimentos no campo da enfermagem oncológica, com ênfase na assistência a crianças em cuidados paliativos, uma vez que as estratégias implementadas neste cenário são coerentes com a Teoria de Jean Watson, pautada nos elementos contidos no Processo *Clinical Caritas*. **Conclusão e Implicações para a prática:** A atuação dos enfermeiros a partir de uma assistência humanizada, com o escopo na promoção de conforto e alívio da dor e nas práticas dialógicas, lúdicas e transpessoais, é imprescindível neste processo de doença. Deste modo, as estratégias identificadas poderão contribuir para a prática clínica de enfermeiros ao cuidar de crianças com câncer em cuidados paliativos, fundamentada na Teoria de Jean Watson.

Palavras-chave: Cuidados Paliativos; Criança; Neoplasia; Enfermagem; Teoria de Enfermagem.

RESUMEN

Objetivo: comprender los cuidados que brindan los enfermeros a los niños con cáncer en cuidados paliativos a la luz de la Teoría de Jean Watson. **Método:** Estudio cualitativo, basado en la Teoría de Jean Watson, realizado con diez enfermeros clínicos de un hospital de referencia en cáncer de João Pessoa, Paraíba. La recolección del material empírico se realizó entre octubre y diciembre de 2020, mediante la técnica de entrevista semiestructurada, posteriormente analizado bajo la Técnica de Análisis de Contenido. **Resultados:** Los testimonios de los enfermeros aportaron fuertes reflexiones sobre el conocimiento en el campo de la enfermería oncológica, con énfasis en la asistencia a los niños en cuidados paliativos, ya que las estrategias implementadas en este escenario son coherentes con la Teoría de Jean Watson, a partir de los elementos contenidos en el Proceso *Clinical Caritas*. **Conclusión e Implicaciones para la práctica:** El papel del enfermero a partir de la prestación de un cuidado humanizado, enfocado en la promoción del confort y del alivio del dolor y en las prácticas dialógicas, lúdicas y transpersonales, es fundamental en este proceso patológico. Así, las estrategias identificadas pueden contribuir para la práctica clínica del enfermero en el cuidado de niños con cáncer en cuidados paliativos, con base en la Teoría de Jean Watson.

Palabras clave: Cuidados Paliativos; Niño; Neoplasma; Enfermería; Teoría de Enfermería.

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INTRODUCTION

Care is part of the essence of the human being, especially with regard to a welcoming, sensitive and loving relationship. With the advent of humanization processes, care came to be considered a new paradigm, being represented by the symbol of the hand that caresses, protects and supports. In this way, it provides a global involvement with those most deprived, through the desire to devote oneself with empathy and promote healing.[1]

Health care – especially palliative care, which aims to improve the quality of life, promote comfort and alleviate the suffering of patients affected by life-threatening diseases and their family members[2] – must be universally accessible, since this approach is responsible for preventing and relieving physical, psychological, social and spiritual pain and suffering, as well as promoting comfort, dignity and well-being. In addition, they must be offered while the patient is being assisted in the face of a potentially fatal disease, including cancer.[3]

According to the World Health Organization, each year, about 400,000 children and adolescents are diagnosed with cancer, which in many countries, including Brazil, represents the leading cause of death in this age group. It is known that early diagnosis enables access to centers specializing in palliative care in the initial phase of the disease, thus promoting comprehensive care based on individual needs, biopsychosocial-spiritual dimensions and the child's quality of life throughout the illness.[4]

To promote palliative care, especially for children with cancer, it is essential to have a multidisciplinary team, aiming at a dialogic and interdisciplinary relationship as a means of establishing an integration channel between the team members themselves and the patients who need this attention to the improvement of the quality of life.[5] Among the professionals who make up this team, nurses stand out, as they are responsible for implementing strategies to provide dignity, comfort, relief from biopsychosocial-spiritual suffering and the rescue of patients' autonomy.[6]

The nurse plays an irreplaceable role in the execution of this assistance, since the direct care of these professionals in the different stages of the disease permeates the therapeutic plan, the management of care directed to the needs that involve the holistic dimensions, as well as the planning and implementation of actions based on humanization, focusing on the uniqueness and subjectivity of the person being cared for.[7]

It is noteworthy that nurses need to support their practice from a theory, and in the face of child hospitalization due to a life-threatening disease, such as cancer, palliative care is efficient by providing an improvement in the quality of life, having as focus meeting physical, psychological, social and spiritual needs, as proposed by Jean Watson's Theory of Human Care.

The hospitalization of children with cancer generates fragility and compromises the restoration of the patient's health and well-being; and Jean Watson's Theory may allow the establishment of the interpersonal relationship between the nurse and the child and the development of an integral and humanized care,[8] also directed to its transcendent aspects and being more effective than curative care, which is not always possible in these cases.[9]

The philosophy and principles of pediatric palliative care are in agreement with Jean Watson's Theory of Human Care, especially given the complexity and need for comprehensive care in this scenario.[9] Thus, this topic is relevant, which justifies the scientific production and the dissemination of new studies to support nurses' practice.

Based on the presented idea, the proposed study was guided by the following question: how does the assistance of nurses to children with cancer in palliative care occur? The objective was, therefore, to understand the assistance of nurses to children with cancer in palliative care in the light of Jean Watson's Theory.

METHOD

This is an exploratory, qualitative field study, guided by Jean Watson's Theory. With the premise of promoting greater scientific rigor, the criteria proposed in the Consolidated Criteria for Reporting Qualitative Research (COREQ) were used as a support tool. They are appreciated in some of the 32 assessment items aimed at studies of a qualitative nature.[10]

The research was carried out in a philanthropic hospital, located in the city of João Pessoa, capital of the state of Paraíba, considered a reference in the region in the treatment of the population affected by cancer in different age groups. It is noteworthy that the hospital has a Palliative Care Commission composed of a multidisciplinary team. In addition, it is the only one in Paraíba that has a High Complexity Assistance Center in Oncology with a pediatric unit.

The study population consisted of nurses who provide direct care to children affected by cancer in palliative care. To select the sample, the following inclusion criteria were considered: that nurses were providing care to children with cancer by means of palliative care during the data collection period; at least six months of assistance to the mentioned group, as this would be a minimum period for acquiring experience in this scenario. Professionals who were not present in the empirical phase of the study or who were away from their work activities due to sick leave, vacations and others were excluded.

In this understanding, of the 25 nurses eligible for the study, distributed among the outpatient, inpatient and intensive care units, ten clinical nurses from the institution selected for the research were included. The number of professionals was considered satisfactory, since in this type of investigation it does not matter the number of participants, but the depth of the study to be investigated. For that, the criterion of saturation of information was used, which emerged from the speeches of the study participants.[11]

The collection of empirical material took place from October to December 2020, through the semi-structured interview technique, guided by a script containing subjective questions, relevant to the objective proposed in the study, namely: In the context of palliative care, which strategies do you use when assisting children with cancer in a way that promotes humanistic values? During care actions, what do you understand by assisting with respect to the basic needs of children with cancer in palliative

care? What strategies do you use to create an environment that enhances the comfort and dignity of children affected by cancer in palliative care? Do you seek to develop and maintain a relationship of trust in your care practice? How do you seek to encourage and support the expression of positive and negative feelings in the field of pediatric oncology? What strategies do you use to creatively solve problems arising from the pediatric oncology care process?

Due to the Covid-19 pandemic, the interviews followed the biosafety protocols recommended by the Ministry of Health, being carried out in a reserved environment, close to the pediatric oncology sector, with an average duration of thirty minutes. For data entering, the recording system was used. The nurses' statements were transcribed in full.

In order to guarantee the anonymity of the participants, pseudonyms referring to the Jean Watson Theory were used, which are included in the elements of the Clinical Caritas Process. The words used for coding were: love; kindness; benevolence; compassion; confidence; care; involvement; empathy; hope; and respect.

To systematize the empirical material, the Content Analysis Technique was used, which aims to describe the content of the information obtained through quantitative and/or qualitative indicators and systematic procedures that lead the researcher to reread the communication process and promote knowledge inference.[12]

Data were analyzed according to the following steps: pre-analysis; codification; inference; and interpretation of data.[12] The pre-analysis was based on data collected from interviews with professionals participating in the study. From this perspective, skimming of the reports was carried out, aiming at a better understanding of the investigated phenomenon. Regarding the second stage, the raw data were coded and aggregated into thematic units. As for the inference and interpretation of the data, these were interpreted and analyzed in the light of Jean Watson's theory, based on the elements of the Clinical Caritas Process and also on the literature relevant to the topic.

The proposed study was approved on October 22, 2020, under Opinion No. 4,354,631 and CAAE: No. 37132920.0.0000.5188, taking into account the ethical principles contained in the Regulatory Guidelines and Standards of Resolution No. 466/12 of the National Council of Health/ Ministry of Health in force in the country for the development of research involving human beings,[13] as well as the ethical principles established in COFEN Resolution nº 564/2017, which establishes the Code of Ethics for Nursing professionals.[14]

RESULTS

The nurses participating in the study are in the age group between 37 and 60 years. Of these, nine were female and one was male. As for the time of work in oncological hospital care, there was a variation from one to 35 years.

For a better understanding of the analysis of the empirical material, three subcategories were created from the nurses' statements, presented below:

Comprehensive and humanized care for children in palliative care, with an emphasis on relieving pain and suffering

The testimonies of the nurses interviewed highlighted the importance of providing assistance aimed at humanized care, with empathy, sensitivity and attention to the individualities and dimensions existing in being a child with cancer in palliative care.

In this view, it is necessary to carry out strategies that minimize the impacts of suffering and pain, which permeate the experience of hospitalization and, consequently, of aggressive therapy, as noted by the following statements:

> *[...] we introduce humanized care, because that child in palliative care usually feels a lot of discomfort. [...]* (KINDNESS).
>
> *We seek to minimize the suffering to which the child is exposed during treatment, with humanized strategies* (BENEVOLENCE).
>
> *[...] our role becomes to provide relief from the suffering presented during palliative treatment [...] When they arrive here, they are already weakened, a lot of humanization is needed* (COMPASSION).
>
> *If they are in pain, we always try to alleviate it [...] We go a long way towards humanizing child care [...] we are always by their side, especially in times of pain. So, we need to be attentive and sensitive to their needs* (EMPATHY).
>
> *Generally, when they report pain, which happens a lot in oncology, we think of strategies to promote their well-being. [...] we see all dimensions* (RESPECT).

Communication to establish trust between the nurse, the child and the family

The testimonies emphasize the importance of verbal and non-verbal communication as necessary strategies in the establishment of a constructive, understanding and trusting relationship, both with the child and with their family, provided they are used in a clear, adequate, effective and confident manner, in order to reduce conflicting situations and misunderstandings.

> *[...] communicating properly with the family in a clear way, before and during each procedure, is always an important strategy [...] I think the help-trust relationship comes from a conversation based on truth [...] it is an essential point for the quality of care. [...] Touching is more than a word, especially in a time of finitude [...] a hug, a handshake, a look [...]* (LOVE).
>
> *I try to be real and get closer, to be friendly, smiley [...] so, it is necessary to talk [...] we, as nurses, detect this*

comfort that we give to the children and the family through the dialogic relationship (CARE).

[...]I always talk to each one and they gain confidence to open up, talk about what they are feeling [...] (INVOLVEMENT).

We talk a lot with them, for them to open up more, trust in each explanation of each procedure and showing that, no matter how painful the procedure is, it is for their own good. [...] I seek through conversation, which is a light technology, to know how they got here, how they discovered the disease, through this bond that we are making (HOPE).

According to the testimonies of some nurses, it is fundamental to understand that there are specificities in communication with children in the face of a care considered complex, since it is essential to adopt techniques to make themselves understood in the different age groups and contexts that differ in the history of each child.

[...] We always try to get closer to them, show more trust [...] all this involves empathy, the security you pass on to the family and the patient [...] depending on the age of the child, knowing how to communicate (KINDNESS).

It's trying to speak a language that the child understands, so we try to understand the child's body language and their expressions and, in this way, help and comfort their pain (BENEVOLENCE).

The ludic as a recreation and comfort strategy for the child with cancer

The nurses emphatically show in their speeches that there is an understanding that playing during the hospitalization period of children with cancer in palliative care has been presented as a strategy that has had great positive impacts, as shown in the following excerpts:

It's taking it to the ludic side, trying to play, doing magic, to make the treatment lighter, provide more comfort [...] In the clinic, there's a toy library, in the chemotherapy infusion room, there's video game, there's television [...] (BENEVOLENCE).

[...] strategies for playing, paintings, drawings, theater and illustrations to alleviate the discomforts of palliative treatment and encourage them with an environment suitable for their age [...] (CONFIANCE).

We like to play with children in palliative care because they feel more comfortable in the procedures, mainly, and the pain decreases [...] here there is television in the rooms, there are many visits from clowns, characters, recreation [...] in a more painful procedure, we try to distract the child, dancing, talking enthusiastically, playing (CARE).

[...] we always encourage these playful activities to promote comfort: drawings, paintings, electronic games, dances and to amuse them, we also sing [...] (EMPATHY).

DISCUSSION

According to the results presented, nurses' assistance to children with cancer in palliative care aims to relieve pain, promote comfort and well-being of these patients, namely: the promotion of humanized care; the communication; and the use of the ludic.

In the testimonies, the importance of the role of nurses in humanized care for children with cancer was evidenced. These statements emphatically corroborate the results of national studies that highlight the need for this care, since this disease causes countless sufferings for infants and their families, such as limiting pain. Treatment often prevents the child from performing common and significant activities for this phase due to the possibility of death, changes in family dynamics and fear of hospitalizations, which end up becoming recurrent.[15,16]

The repercussions of cancer in the lives of children and their families cause impacts not only in the physiological field.[17] Therefore, it is essential that health professionals develop and establish care based on comprehensiveness, that is, beyond attention to physical pain. They must be able to perceive pains of the mind and spirit in a sensitive and transpersonal way, giving them a place of importance in the care plan.[18] In this sense, Jean Watson emphasizes that the one being cared for is constituted by biopsychosocial-spiritual dimensions that need to be perceived, cared for and respected, so that there are improvements in the well-being of these patients and the improvement of care.[19]

In this way, pain relief strategies through actions that provide the guarantee of comfort, as well as a better response to treatment, are part of the foundations of a personalized and unique care provided by nurses to children with cancer and their families,[15] given that painful sensations affect 50% of patients throughout the process of coping with cancer.[20]

These strategies are in line with the recent regulation of the World Health Organization (WHO), which advocates actions compatible with humanization policies. These actions are effective in controlling pain and minimizing suffering, reducing complaints from these patients by up to 80%.[20]

In this context, having instruments that can be incorporated into practice, such as the elements of the Clinical Caritas Process – practicing loving-kindness, being authentically present in care, cultivating spiritual practices, establishing a relationship of trust, accepting without judging the belief system of the one being cared for, among other elements –, are consistent with the principles and practices of humanization of care,[21] and make them an essential activity for life with regard to the implementation of palliative care, thus minimizing suffering in the surroundings of the life of people with oncological disease.[22]

Guided by humanistic values, the Clinical Caritas Process allows nurses to break with the biological paradigm by proposing

a way to achieve transpersonality in care from a unique care relationship based on trust, bonding and intentionality, demanding from this professional, in addition to attitudes of attention, zeal and affection, knowledge and skills to perceive, welcome and communicate.[23]

From this perspective, communication emerges as fundamental for palliative care, being essential for the creation, maintenance and strengthening of bonds, since it facilitates the perception and prioritization of health needs. It also allows for the individualization of care and the qualification of assistance, promotes feelings of security and well-being that positively influence the well-being of the child, and is therefore considered one of the fundamental pillars of palliative care.[24] In addition, it is shown as an indispensable channel of emotional support for the child's family, which also shares the suffering and anguish involved in the entire illness process.[25]

Cancer imposes changes in routine and social interaction to the child, which can lead to social and affective isolation, as well as difficulty in adapting and accepting care. Such effects can be minimized when using effective communication, which is made clear and understandable, respecting the child's cognitive and emotional development, especially in the use of verbal language.[26]

The nurse must be sensitive to the expressions, gestures and behaviors of the child who, many times, does not know or cannot express themselves verbally. In this sense, the need to establish a help-trust relationship, an element present in the Clinical Caritas Process, is necessary in the communication process.[27] In this way, inserting this interaction strategy requires the nurse to be authentically present, available, attentive, seeking in their practice to be respectful and connect with patients to recognize care needs, such as: the therapeutic touch, welcoming look and smile as important tools in promoting comfort and well-being.[26]

In addition, providing clear and sufficient information about the child's health situation to the child and their family members is an attitude of respect that promotes trust between them and the health professionals, values the autonomy of the child and their family, and assists in future decision-making, in care planning and in coping with the disease.[24,25] Corroborating our findings, a study carried out with 13 children and adolescents hospitalized in an oncology hospital in the southern region of Brazil highlighted the satisfaction of these patients in receiving information from health professionals about their clinical condition, recognizing such care as a remarkable moment of interaction with the team and strengthening of the bond.[26]

It is worth mentioning that the establishment of effective communication is something challenging for nursing professionals, either because of the fear of inadequate understanding of the information by the children, or because of the fear of causing more suffering to them when communicating some difficult news, a fact that can make difficult the performance of the palliative nurse team.[25,26]

In addition, children, for the most part, associate the hospital with a bad environment, of deprivation, in which there is a distance from family and friends, where invasive techniques are performed and whose routines need to be followed, including limitations for playing games. Although the practice of recreational activities is limited in this environment,[28] it was possible to verify the performance of several activities by nursing professionals, as indicated by the statements of the third category.

Playing, toy therapy, the toy library, painting, drawing, electronic games, theater plays, performing magic, clown therapy, television, recreation, dancing and singing are strategies used by these professionals during assistance that facilitates the relief of pain and discomfort faced by oncological disease and its therapy, making the treatment lighter and allowing the child to feel better, livelier, and able to smile even in the face of a life-threatening disease, thus promoting their rights to recreation as well as improving their health status.[29]

In this understanding, the creativity of the nurses interviewed when working in the care of children with cancer is perceived, as proposed by Jean Watson, in one of the elements of the Clinical Caritas Process that guides the professional to be creative and use creativity in all forms of knowledge for the resolution of problems.[30]

In the oncology environment, it is pertinent that nurses meet the needs of children and include playful activities in their care, since in the face of a life-threatening disease, playing will provide opportunities for minimizing pain, suffering and other manifestations that this patient experiences. In this way, playing becomes a tool of great relevance in the child's coping with cancer.[28]

A study carried out in a public hospital with the objective of describing the perception of 20 hospitalized children about activities with music found that playing allowed a therapeutic, welcoming and affectionate environment for children and their families, in a way capable of promoting health and preventing aggravations related to hospitalization.[31]

The playfulness present in the nurses' statements reveals the promotion of a fun, creative and healing environment. Providing a healing environment at all levels is also recommended by the theorist Jean Watson, in the elements of the Clinical Caritas Process.[30] Playful activities enable care that meets the needs of the child and assistance that contemplates all dimensions of being cared for, since, in addition to relieving physical suffering, the child can play, be distracted, socialize with other children, with the team, express feelings in the face of illness and hospitalization and, consequently, improve their well-being.

It is important to emphasize that recreational activities can bring the child closer to the nursing team. A study carried out with nurses pointed out that these activities provide a better relationship between the professional, the child and the family, by allowing the bond, approximation, interaction and well-being, also facilitating the work of the team during the hospitalization time.[32]

Another study, with a systematic review, showed that recreational activities led to the reduction of negative feelings, complaints of pain, nausea, anxiety, depressive feelings and improved communication. Therefore, playing can be incorporated as a strategy into the nursing care plan, without harm to the patient and their clinical practice.[33]

Considering this view, the categories discussed here brought strong reflections about knowledge in the field of oncology nursing, with an emphasis on assistance to children in palliative care, since the strategies implemented in this scenario are consistent with Jean Watson's Theory, based on the elements contained in the Clinical Caritas Process.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The study highlighted the assistance of nurses based on Jean Watson's Theory of Human Care, when caring for children with cancer in palliative care. From the qualitative analysis of the empirical material, the strategies implemented for palliative care for children with cancer by the professionals participating in the study were identified. The strategies contemplated the elements of the Clinical Caritas Process.

From this perspective, it was possible to verify that nursing care aims to meet the different needs of the patient, in addition to biological care, basing its practice on humanistic factors and scientific knowledge, in line with Jean Watson's Theory.

Thus, based on Jean Watson's Theory, nursing care is capable of offering humanized and comprehensive care, which attends to the child with cancer in palliative care in all its biopsychosocial-spiritual dimensions with the scope of promoting comfort and pain relief through playful, dialogic, creative, loving and transpersonal practices.

The limitations of this study were mainly due to the difficulty in contacting the nurses of the institution chosen for the study, due to the pandemic context. However, this restriction was circumvented and the quality of the study was not compromised.

In view of the above, this study may support the clinical practice of nursing professionals in the context of pediatric oncology, as it provides reflections for a sensitive look at humanized care through the philosophy of palliative care, in order to overcome the biomedical/hospital-centric model. Furthermore, it opens new horizons in the fields of care, teaching and research, through the improvement and transformation of nursing care, based on the elements described here.

AUTHOR'S CONTRIBUTIONS

Study design. Thainá Karoline Costa Dias.

Data collection. Thainá Karoline Costa Dias.

Data analysis. Thainá Karoline Costa Dias.

Interpretation of the results. Thainá Karoline Costa Dias.

Writing and critical review of the manuscript. Thainá Karoline Costa Dias. Altamira Pereira da Silva Reichert. Carla Braz Evangelista. Patrícia Serpa de Souza Batista. Eliane Cristina da Silva Buck. Jael Rúbia Figueiredo de Sá França

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